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Bereavement care: parents and professionals

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BEREAVEMENT CARE: PARENTS AND PROFESSIONALS

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Parental experience of grief

Jones, Kerry (2014). Parental identity in narratives of grief following perinatal death. *Grief Matters: The Australian Journal of Grief and Bereavement*, 17(2) pp. 38-42.

- ▣ Perinatal death - a child who is stillborn or who dies in the neonatal period in the first four weeks of life
- ▣ Narratives reveal how sense of self and identity is mediated by the social and cultural milieu to which parents belong
- ▣ Largely disenfranchising experiences
- ▣ Others fail to acknowledge the enormity of the event.
- ▣ Parents experiencing depression, anxiety, PTSD (O'Leary, 2009) ▣ Struggle with profound sense of guilt and purposelessness
- ▣ Reproductive success is considered a critical part of the life course
- ▣ Represent a death of part of the self as well as that of

- ▣ 1 in every 200 babies is stillborn
- ▣ 1 in every 300 babies dies in the first few weeks of life
- ▣ Most common form of mortality in early life (Office for National Statistics, 2013; Redshawe et al, 2014).
- ▣ Studies with bereaved parents that compared to child death in later years
- ▣ Perinatal death is not recognised as an event that is tragic or worthy of mourning
- ▣ Referred to as an invisible death (Cacciatore, 2010;Kelley, 2011)

- ▣ Death challenges parental expectations due to discourse that surrounds pregnancy and childbirth
- ▣ Frames such experiences in a positive light
- ▣ Fails to acknowledge experiences that end in a way that many had unanticipated. T
- ▣ his changes identity and a sense of self
- ▣ Deaths represent a disruption to the life course of siblings and other family members such as grandparents (Jones, 2014; Murphy, 2014).

- ▣ Events that are narrated are ways of establishing and reaffirming identity
- ▣ Depends if narrations are rejected or accepted by others
- ▣ Resources or restraints in claiming parental identity
- ▣ Research with bereaved parents - parents construct narratives, share autobiographical accounts
- ▣ Listeners who guide the narrator as to what is acceptable and what is silenced

- ▣ Birth/ death becomes invisible
- ▣ Creates ambivalent sense of identity
- ▣ Betwixt and between that of a non- parent and bereaved parent of a deceased baby
- ▣ Parental identity is far more complex than simply an either or status
- ▣ Search for meaning and find ways to memorialise their child
- ▣ A way of maintaining a relationship with the deceased baby so that it co-exists in the survivor's daily life while they re-evaluate their identity (Klass, 1996:197)

Responses to loss from others

“I have tried to discuss it [death of a baby] with my mother and she changes the subject every single time. She finds it very uncomfortable so I just stopped bringing it up. I would have thought that the one thing, the one person and the one place where I could get the most support and it ended up being the least supportive. I found more support through a group and a company of strangers than I did from my own family.”

Experiencing professionals

“ One midwife she was so lovely she even brought in a present for my son (sibling) and that really felt like we mattered, what was happening to us mattered. The other midwife on another shift was all bussly and all about ticking off a list, she didn't appreciate that I was near other mother's who had their babies, and I found this really hard. I couldn't wait to get out of there.”

On bereaved parents

- ▣ All parents experienced a sense of ambivalence about their status as a parent
- ▣ Path to parenthood disrupted and sense of self and identity mediated by others
- ▣ Acknowledgment and personification aided a sense of coping
- ▣ For most parents - turning to a group of strangers to negotiate their identity and assert that there had been a baby with real things
- ▣ The groups are a way of negotiating a sense of identity and exploring the futility of previous assumptions about pregnancies and birth.

NURSES EXPERIENCES

- ▣ Several studies - midwives experiences of caring for families who experience perinatal death. (Jonas-Simpson et al, 2010).
- ▣ Very difficult and requiring courage but it was also an experience that they valued and felt privileged to have.
- ▣ Support from colleagues who listened and understood when they could not find this from their family and friends.
- ▣ Nurses worked hard to comfort bereaved families and wondered how they would continue on after leaving the hospital.
- ▣ Support group for nurses would be helpful

Education

- ▣ Limited preparation for encountering the phenomenon of grieving in formal nursing education
- ▣ Few nursing curriculums include courses on death and dying and, we would add, the human experience of grieving a loss.
- ▣ Education along with support is “useful in helping staff to develop coping strategies and manage their responses to death” (Wilson & Kirshbaum, 2011 p. 563).
- ▣ “the goal of quality bereavement care will be enhanced by addressing the educational and training needs of nurses” (Chan et al, 2010 p. 531).

Themes

- ▣ *Growth and transformation emerging with the anguish of grief,*
- ▣ *Personal and professional impact,*
- ▣ *Support from colleagues and others providing authentic, compassionate, quality care*
- ▣ *Education and mentorship*

(Jonas-Simpson et al, 2013)

- ▣ Experiencing grief while with families who experienced a perinatal loss as “an emptiness,” also a rewarding experience that inspired change and growth.

“I will still remember that experience because it changed me, it changed me, who I am, it changed me, everything, emotionally because that was really a close experience, because I never had a baby die [in my practice before].”

- ▣ Discomfort shifts in time...

“a very traumatic experience” when a baby died while she was working. She said, she “shied away from ever caring for a woman undergoing a loss for a very long time after that”

- ▣ Comfort with death grew and an ability to be with those who were bereaved developed.

“When I first started doing the work, as I said . . . I was very nervous, and I found that it almost took away from my support with the families because I was so nervous. I didn’t know what to say, I felt awkward. I felt terrible for the families but didn’t know how to support them except for just being there making them comfortable. So, when I say I think I have grown, I feel like now I am sort of able to take the younger nurses or the newer nurses under my wing and tell them it is okay to talk about it, it is okay to feel while you are in there. It is okay to cry that sort of thing. So I feel that maybe it is a comfort level thing. So maybe I am just more comfortable with it. Each experience is unique and each experience is devastating.” (Jonas-Simpson et al, 2013 p.4)

Personal and professional impact

- ▣ Having to leave some patients for a moment to “collect” herself
- ▣ After seven babies were stillborn in 1 month, she felt she was going to “lose it.”
- ▣ Personal losses and how these influenced their practices, such as knowing it is important to have someone to be with and listen and knowing when their grief may interfere with care.
- ▣ How hurtful it was when some did not acknowledge her loss.
- ▣ This helped in understanding the importance of being present and listening to the bereaved.
- ▣ Nurses also spoke of taking their grief home (e.g., coming home sad) and how it was at times difficult not to.

- ▣ “I would usually say to my family you know what, this was tough, I experienced looking after a family that had a loss or [the baby] died soon after birth and they always knew to sort of give me space.
- ▣ “I have a daughter, so you get to cherish everything that she does, and you get to connect with her. She is everything . . . you get to understand, what the [bereaved] mother was feeling, although it was different because it was her own unique experience.” (Jonas-Simpson et al, 2013, P.5)

Isolation

“Sometimes I am much more withdrawn, socially withdrawn. I turn down more social invitations than I accept, because people will say, “So how is your job?” I have gotten to the point where I don’t even want to talk about it anymore, because it is not a happy place to work. So it has impacted me.” (Jonas-Simpson et al, 2013, P.6

Support from colleagues

“It is very therapeutic to be able to talk about your experiences after the shift, and sometimes the birth occurred just at the end of your shift and you were done and you went home, and I always missed the opportunity to chat. And so I would keep some of those things inside of me and then it took longer to — the grieving was different if I wasn’t able to share that soon after the experience. It was definitely helpful to process my own grieving if I had a colleague there that could connect with me. “ (Jonas-Simpson et al, 2013, P.7)

Creating mementoes

“We have an excellent bereavement package and . . . we try and collect as many mementos from the baby and I am not so good with collecting the hair samples, I must say, the little ones, it is just impossible, but the hand and the foot prints, Oh my God, so, so meaningful . . . The parents are so appreciative of that it is just great.” (Jonas-Simpson et al, 2013 P. 7)

Education and mentorship

- ▣ taking courses, discomfort shifts to comfort.
- ▣ Tips - be authentic, seek knowledge, mentorship, and support and listen to families.
- ▣ Bereavement mentors
- ▣ Bereavement education in schools, in orientation, and also provided widely to the public.
- ▣ The right to grieve if not - disenfranchised

SANDS

- ▣ raise awareness of parents and familial grief
- ▣ provide training to health professionals
- ▣ Support parents by phone, online they have over 150 support groups across the UK.
- ▣ OU/SANDS research - models of bereavement support for parents
- ▣ SANDS concern for adequate support - Bereavement Care Report 2010, Audit of maternity units, 2016

“By ensuring that parents receive care that is *clinically skilled, emotionally intelligent*, consistent and authentically caring, there is the best chance that, even in the midst of a difficult situation, they will have the healthiest experience possible, as well as the best chance of achieving optimum well-being in the longer term. Staff in all relevant health settings need to be supported and encouraged to recognise and respond to their one chance to get it right, for the sake of all future parents who experience such a loss.” (Downe et al, 2013)

Bereavement support midwives

- ▣ Information and support resource with links to coroner's , mortuary, funeral directors, registrar of births and deaths, local GP practices, SANDS
- ▣ Supporting staff who come into contact with bereaved parents at any stage of their care in hospital
- ▣ Not sole responsibility - not possible for one individual to manage all issues relating to bereavement on a maternity unit
- ▣ Focus should be on up skilling their colleagues to develop a team which is competent and confident in delivering bereavement care

Training

- ▣ Bereaved parents and healthcare professionals have both identified that bereavement care training for staff is crucial (Downe et al, 2013; NHS Improving Quality, 2014; Redshaw et al, 2014).
- ▣ Parents' experiences of care last a lifetime
- ▣ Critical that staff have support and training in order to deliver appropriate standards of care.
- ▣ Improving skills and knowledge also increases the confidence of professionals
- ▣ Reduces stress (Kenworthy and Kirkham, 2011)

- ▣ Providing emotional support for staff
- ▣ Bereavement rooms
- ▣ Taking baby out of hospital
- ▣ Other support services
- ▣ Communication
- ▣ Translation services – similarly trained
- ▣ Not left to husband or children to converse
- ▣ Post mortem

To Conclude...

- ▣ The quality of care that bereaved families receive when their baby dies can last a long time
- ▣ Good care can't remove pain but poor care makes it much worse
- ▣ Crucial to support health professionals and to ensure training is mandatory
- ▣ Excellent mentorship
- ▣ Opportunity to acknowledge and affirm professional experiences
- ▣ To reduce isolation
- ▣ When grief is acknowledged, nurses may feel better supported
- ▣ lead to enhanced nursing practice and quality care for bereaved families
- ▣ Enhancing quality of work and home life for professionals

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Thank you for listening.



Little Footprints